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Citation for published version (APA):

Hunter, L., Sparrow, E., Modi, N., & Greenough, A. (2017). Advancing child health research in the UK: the Royal College Research Charter. *Archives of Disease in Childhood*, 102(4), 299-300.

Citing this paper

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Advancing child health research in the UK: the Royal College of Paediatrics and Child Health

Infants' Children's and Young People's Research Charter

<http://www.rcpch.ac.uk/cyp-research-charter>

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Keywords:

Research

Children

Child Health

Charter

Child Health Charter

Word count: 1309

SUMMARY

The Royal College of Paediatrics and Child Health (RCPCH) has developed an Infants' Children's and Young People's Research Charter. It was developed with the engagement of children and young people through the RCPCH's & Us® network. The Charter and the accompanying "what you need to know" information guide and a "useful resources and external links" guide were designed to support children, young people, their families and healthcare professionals in discussions about research issues.

The participation of children, young people and their families is an important component of the child health research process. Children and young people's right to participate in and benefit from research is laid out in the United Nations Convention on the Rights of the Child (UNCRC).[1] Researchers and healthcare professionals have a duty to respect, protect and help fulfil those rights. The Ethical Research Involving Children Partnership [2] built on the work of the UNCRC and produced the International Charter for Ethical Research Involving Children. It called on researchers to be open, reflective and collaborative in their ethical decision making. In recent years, there has been considerable activity in the UK advancing this agenda. INVOLVE [3] was established in 1996 to support active public involvement in the NHS, public health and social care research. This is now funded by the National Institute of Health Research (NIHR), as is the Generation R network, a national young people's advisory group with local groups across the UK to support the design and delivery of paediatric research. Organisations, such as the Nuffield Council [4], have determined how healthcare professionals can ethically involve children and young people in research to ensure healthcare services are safe and effective. This has begun a cultural shift in perceptions about involving children and young people in research design and delivery. It, however, continues to be important that all the perceived barriers to involvement of infants, children and young people in research are removed.[2-5]

In 2012, the Royal College of Paediatrics and Child health (RCPCH) “Turning the Tide” report [5] highlighted the importance of child health research. It emphasized the need for the RCPCH to set out the expectations of children, young people and their families with regard to research to understand the biology of health and disease, reduce uncertainties in treatments and improve health care delivery. The report stated it was essential to support clinicians to involve infants, children and young people in research and recommended the development of a Children’s Research Charter to highlight the importance of child health research and promote active involvement.

This paper describes the development of the Research **& Us®** Infants’, Children’s and Young People’s Child Health Research Charter (henceforth referred to as the Charter). It was developed with the engagement of children and young people through the RCPCH’s **& Us®** network, which is a large collaborative network enabling children, young people and parents and carers to have a voice in improving healthcare services and achieving better outcomes. The Charter was designed to support children, young people, their families and healthcare professionals in discussions about research issues.

A literature review was carried out to identify studies of children and young people’s involvement in research. Twenty-three relevant publications were identified, they emphasized key themes as communication, empowerment and the support needed to involve children and young people in research. The results were then supplemented with the results of discussions with key stakeholders which included the Nuffield Council of Bioethics, Generation R and the International Children’s Advisory Network (iCAN). Those sources informed the development of a series of consultation workshops with children and young people. The workshops highlighted that children and young people wanted to be given the opportunity to be involved in research, not only as a participant, but also in the design of research studies. They wanted the chance to help other children and young people and share experiences of research with others. The children and young people

wanted professionals to speak about research positively, but to choose their words carefully avoiding those with potentially negative interpretations such as “trial” or “investigate”. Both words made the children and young people think about errors and mistakes. From these events, eight principles emerged that were then sent out for consultation. The Charter, a “what you need to know” information guide and a “useful resources and external links” guide were then developed.

The draft Charter and guides were then released for external consultation. Two surveys were undertaken, one of children, young people, parents and carers and one of healthcare professionals and organisations. Children, young people, parents and carers were also invited to comment on the charter documents through the **& Us®** network. The healthcare professionals’ survey was distributed through the RCPCH’s stakeholder network. The network includes professionals (research nurses, research teams, clinical academics), organisations (the Nuffield Council on Bioethics, Generation R, iCAN, INVOLVE), the collaborative for child health engagement leads, the research leads for the UK paediatric speciality groups, the NIHR clinical study groups, the RCPCH research strategy committee and the UK Child Health Research Collaboration. The survey was also available to all members to complete on the RCPCH website. The responses to the surveys highlighted the need to increase the commitment to child health research and improve access to research training and supporting materials, as well as ensure more time for researchers and resources to support them. This enabled refinement of the Charter principles, which were then written in a format guided by the children and young people.

Twenty-three publications were identified in the literature review. Fifty-six children and young people took part in the workshops as part of the RCPCH England Takeover Challenge and **& Us®** Roadshows. Key themes emerged including children and young people wanted to be given the opportunity to be involved in research not only as a participant, but also in the design of research studies. They wanted the chance to help other

children and young people and share experiences of research with others. The groups wanted professionals to speak about research positively, but to choose their words carefully avoiding those with potentially negative interpretations such as “trial” or “investigate”. Both words made the children and young people think about errors and mistakes. From these events, eight principles emerged that were then sent out for consultation.

Seventy-three children and young people, seven parents and 41 child health professionals responded to the surveys. Their responses highlighted the need to increase the commitment to child health research and improve access to research training and supporting materials, as well as ensure more time for researchers and resources to support them. This enabled refinement of the Charter principles, which were then written in a format guided by the children and young people.

The Charter (Figure 1) was launched at the RCPCH Annual Conference in April 2016. The Charter provides a framework for those involved in child health research. It asserts the views of children and young people, promoting the rights of children and young people to be involved in research and for them to be supported to be engaged and empowered in the research process. A “what you need to know guide” and “external resources and useful links guide” accompanies the Charter to provide guidance and direct professionals to useful tools and e-learning. The Charter has been disseminated through a wide network of stakeholders and is supported by the Nuffield Council on Bioethics, UNICEF’s Office of Research Innocenti and the International Children’s Advisory Network. It and the accompanying guides are available on the RCPCH website.

The UNCRC [1] is the most complete statement of children’s rights and is ratified worldwide. It has been adopted by countries across the world and forms the basis for other charters which assert the rights of children in various settings. The Research **& Us**® Charter has built on the work of the UNCRC, the Ethical Research Involving Children partnership [2] and

Turning the Tide.[5] Following the launch of Charter, the RCPCH team attended the iCAN conference to gather feedback from young people who attended from across the world. This feedback will be used to further develop the Charter and its use will then be evaluated. The Charter is an important component of the work the RCPCH is undertaking to increase research in child health. We hope the Charter and associated materials will be used widely, and welcome feedback.

ACKNOWLEDGEMENTS

Competing interests: None declared

Contributor statement: LH and ES undertook the literature review and delivered the workshops. AG supported the development work and NM identified the need for a Research Charter. All the authors were involved in the production of the manuscript.

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FIGURE LEGEND

Figure 1: The research **& Us@**: Infants', Children's and Young People's Child Health Research Charter